



EHDS

HealthData@EU Pilot

HealthData@EU Pilot*xSHARE

28 November 2024

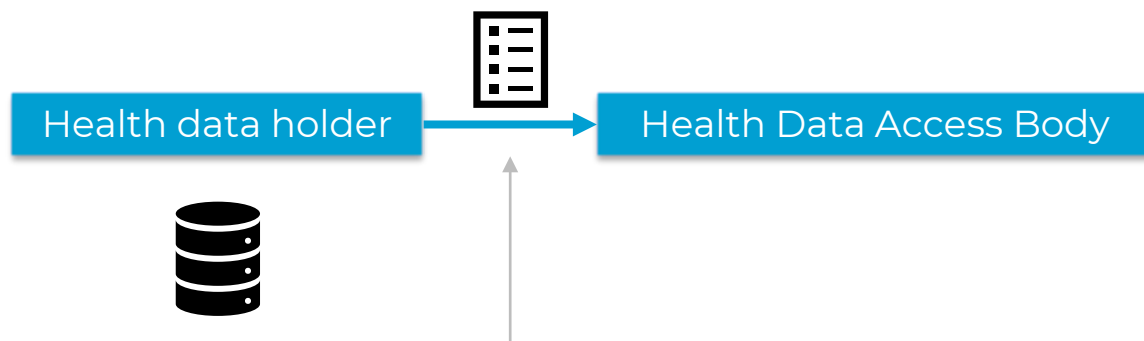


Co-funded by
the European Union

HealthData@ EU Pilot study

- The project has built a pilot version of the European Health Data Space (EHDS) infrastructure for the secondary use of health data “HealthData@EU”
- Technical WPs
 - IT infrastructure: connection to the EU central services
 - Metadata standards: standardizing descriptive metadata
 - Regulatory & legal compliance: data access request form
 - Data interoperability, quality & protection
 - Use cases

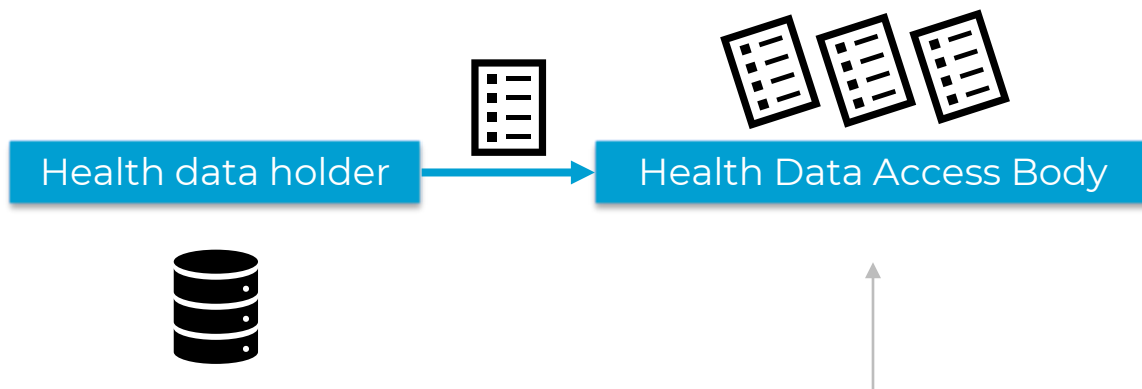
Vision EU



Article 41: *Duties of health data holders*

The health data holder shall communicate to the health data access body **a description of the dataset** it holds

Vision EU



Article 55: Dataset description and datasets catalogue

The health data access body shall, through a **publicly available and standardized machine-readable datasets catalogue**, provide information, in the form of metadata, about the available datasets and their characteristics.

A description of each dataset shall include information concerning **the source, the scope, the main characteristics, the nature of electronic health data and the conditions for making electronic health data available.**

Vision EU



Article 57: EU Datasets Catalogue

The Commission shall establish and publicly provide an **EU Datasets Catalogue** connecting the national datasets catalogues established by the health data access bodies in each Member State as well as datasets catalogues of authorized participants in HealthData@EU.

Why DCAT-AP?

Data Spaces

The European Data Strategy, along with supporting EU policies such as the EHDS Regulation, places data and data sharing at the heart of the digital transformation.

A key pillar of this transformation is the creation of common European data spaces. These spaces will form a unified, federated data infrastructure across Europe, ensuring data openness, transparency, and sovereignty.



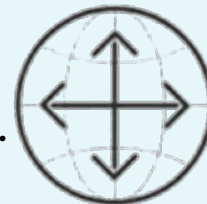
DCAT

DCAT-AP (Data Catalog Vocabulary Application Profile) is revolutionising data interoperability across European Data Spaces.

DCAT-AP helps to harmonise metadata descriptions across diverse sectors and domains

DCAT-AP serves as the backbone for uniting diverse data infrastructures, enabling a harmonised and federated approach to data discovery and access across Europe.

DCAT-AP is adaptable and can be extended to meet specific needs.



Timeline

2022

Landscape analysis

Landscape analysis of the descriptive metadata standards currently in use by the different partners/nodes if they have a metadata catalogue and the health data providers needed by every use case

- [Milestone: MS6.1 Report on landscape analysis](#)

2023

Health DCAT-AP extension

- Training on DCAT-AP provided by the EC webinar
- Working groups to design the new properties and specs of the Health DCAT-AP extension

- [Milestone: Technical Working Group minutes](#)
- [Deliverable: Health DCAT-AP specifications](#)

2024

Implementation

- Implementation of the extension by the nodes and the health data providers needed by every use case
- Management of the development of the central search portal and integration of the common EU metadata catalogue

- Milestone: Report on the implementation of the health DCAT extension by the nodes
- Deliverable: Report on recommendations and further developments

HealthDCAT-AP

- HealthDCAT-AP extends DCAT-AP by including:
 - additional classes and properties;
 - additional recommendations on the use of classes and properties;
 - additional controlled vocabularies.
- HealthDCAT-AP is a health-related extension of the DCAT application profile
- HealthDCAT-AP establishes a standardized description of datasets for all health catalogues
- HealthDCAT-AP aims to standardize health metadata within the scope of EHDS
- HealthDCAT-AP fosters greater interoperability, findability and accessibility of electronic health data across the EU.

HealthDCAT-AP

Unofficial Draft

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HealthDCAT-AP

Unofficial Draft 22 December 2023

▼ More details about this document

Latest published version:

<https://healthdcat-ap.github.io/>

Latest editor's draft:

<https://healthDCAT-AP.github.io>

History:

[Commit history](#)

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Feedback:

[GitHub healthDCAT-AP/draft](#) (pull requests, new issue, open issues)

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HealthDCAT-AP

NEW PROPERTIES

alternative
analytics
code values
coding system
health category
health data access body
health theme
legal basis
max typical age
min typical age
number of records
number of unique individuals
personal data
population coverage
publisher note, publisher type
purpose
quality annotation
retention period

NEW CONTROLLED VOCABULARIES

Based on Art.33

Contact Point Registry of the Health Data Access Bodies, the Union data access service and authorised participants of the healthData@EU infrastructure

Wikidata as an ontological health database

Health Publisher type

CARDINALITIES & USAGE NOTES

General increase of the cardinalities to create rich metadata:

- Open data
- Protected data
- Sensitive data

Technical properties as mandatory properties to operationalise the healthData@EU infrastructure

Recommended Sample distributions:

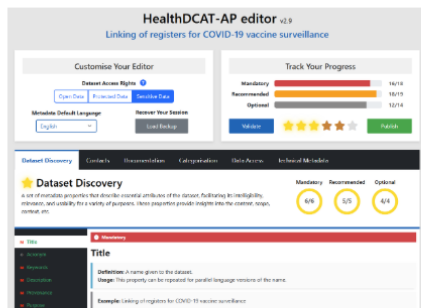
- use of synthetic or anonymized subsets
- use of CSVW terms for RDF-izing variable descriptions

Sciensano's HealthDCAT-AP editor



www.healthinformationportal.eu

Sciensano's HealthDCAT-AP editor



HealthDCAT AP Editor

The European Health Information Portal is glad to offer to all data holders the possibility to create a HealthDCAT-AP compliant metadata record of their dataset, in RDF formats, through its **HealthDCAT-AP editor**.

[READ MORE](#)

Project legacy and further interactions



TEHDAS 2

WP5 Data discovery



Central services

Functional analysis



QUANTUM

Quality annotation



Direct Grant EHDS2

CoP SG Dataset



Other

SHAIPED



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